NIH STRATEGIC RESEARCH PLAN TO REDUCE AND ULTIMATELY ELIMINATE HEALTH DISPARITIES

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

MISSION STATEMENT:

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) supports basic, clinical, and epidemiologic research, research training, and information programs on diseases of bones, muscles, joints, and skin. Most of these diseases are chronic and many cause life-long pain, disability, or disfigurement; they afflict millions of Americans; cause tremendous human suffering; and cost the United States economy billions of dollars in health care and lost productivity. These diseases affect people of all ages, racial and ethnic populations, and economic groups -- almost every household in America is affected in some way by one or more of these diseases. Many of these diseases within our mandate affect women and minorities disproportionately B both in increased numbers and increased severity of the diseases. We are committed to uncovering the bases of these gender, racial, and ethnic disparities and devising effective strategies to treat them.

OVERVIEW OF THE NIAMS STRATEGY FOR ADDRESSING HEALTH DISPARITIES:

The NIAMS has approached the research challenges and opportunities in addressing health disparities by utilizing a broad array of strategies. We have a commitment to maintaining a diverse research portfolio - we invest in our numerous areas using many approaches. Basic research is continuing to uncover many of the most fundamental mechanisms of life and is elucidating strategies for conquering clinical challenges. We take the lessons of basic research and translate them to the clinical arena -- known as "bench to bedside" research. Conversely, research also moves from "bedside to bench," and clinical research can be very useful in providing clues to basic mechanisms. These basic/clinical interactions and translations have served to lay a strong foundation for the present and provide many research opportunities for the future. Research being supported by the NIAMS provides for better diagnosis and treatment, as well as potentially for prevention, of many of the most common, disabling, costly, and chronic diseases compromising life for the American people B diseases that often affect women and minorities disproportionately. Our specific strategies for addressing health disparities in research, research infrastructure, and community outreach are included within each of these sections below.

NIAMS PROCESS FOR SETTING RESEARCH PRIORITIES:

The strategic priorities of the NIAMS are established with input from a whole array of participants. When the Director of NIAMS makes an assessment of research plans that are proposed, he considers the perspectives and advice of a wide range of participants. We are convinced that this broad base of participation strengthens our planning process considerably and thereby strengthens our research strategies.

These participants include:

- ***Within the NIAMS***: the Institute Director, the Scientific Director, Extramural Program Directors; staff of the Office of the Director (including Budget, Planning, Legislative offices); scientists supported by the NIAMS on the NIH campus and around the country; and members of the NIAMS Advisory Council

- ***Within Other Parts of the Federal Government***: Directors and Program Directors in other NIH Institutes and Centers; scientists supported by other NIH components; the NIH Director; Interagency Coordinating Committees (such as the Federal Working Group on Bone Diseases); and the Secretary and key staff in the Department of Health and Human Services

- ***Outside of the Federal Government***: Experts in small panel meetings in discrete research areas; and experts participating in scientific workshops, conferences, and meetings

- ***Members of Voluntary and Professional Organizations***

- ***Members of Congress***

- ***American Public***

It must be noted that the goals and initiatives delineated are not listed in priority order. There is little, if any, reference to the mechanisms that should be used to pursue these priorities; and considerations of the cost of pursuing these initiatives are not emphasized. This plan is not "set in stone" - our planning process is dynamic and fluid, always evolving based on our experience and progress in research. The dynamics come from constant interactions among our staff and scientific and lay groups. Our Institute's Strategic Plan for Reducing Health Disparities was developed with broad input, and was reviewed and endorsed by the NIAMS Advisory Council at its September 1999 meeting. Following that meeting, the draft plan was made available on the Institute's Web Site and broad comment was solicited. Comments were received from many individuals as well as from voluntary and professional organizations. All comments were considered. The plan was submitted to Dr. Harold Varmus, then Director of the NIH in December 1999. We have posted the final plan on our Web site, and we continue to receive public comments and requests for more information on our programs in health disparities. We

are committed to having our plans and our programs fully accessible to the public, as we recognize that we are entrusted stewards of public funds and accountable to the American people to improve their health and the quality of their lives.

NIH RESEARCH GOALS

The overall research goals are to advance the understanding and treatment of diseases within our mandate that affect women and minorities disproportionately, with a particular focus on lupus, scleroderma, osteoarthritis, vitiligo, and keloids.

AREAS OF EMPHASIS:

C ***LUPUS***

Lupus is a serious and potentially fatal autoimmune disease, often occurring in women of child-bearing age. It can affect many parts of the body, including the joints, skin, kidneys, heart, lungs, blood vessels, and brain. People of all races can have lupus; however, African American women have a three times higher incidence (number of new cases) and mortality than white women. They tend to develop the disease at a younger age than white women and to develop more serious complications. Nine times more women than men have lupus, and it is also more common in women of Hispanic, Asian, and Native American descent.

The NIAMS has undertaken a multi-pronged approach to this disease -- supporting research across the full spectrum from basic research to animal studies to clinical studies and clinical trials to prevention through identification of modifiable risk factors. It is only through these studies on multiple fronts that we can fully understand, diagnose, treat, and prevent lupus. Considerable research has been focused on addressing the relationship of socioeconomic, demographic, cultural, immunogenetic, and clinical variables to the course of disease and outcome in Hispanic, African American, and Caucasian lupus patients. A study supported by the NIAMS since 1993, Lupus in Minority Populations: Nature vs. Nurture (LUMINA), demonstrated that Hispanic and African American lupus patients have more severe disease at the time of presentation than Caucasian patients. The study also found that genetic factors appear to be more important than socioeconomic determinants in influencing disease activity at onset of disease. Genetic studies have provided important clues about lupus, and the NIAMS has a long and productive history of supporting such studies in patients and their family members. Previously reported studies have identified genetic factors that predispose African American lupus patients to more severe kidney disease.

With regard to modifiable risk factors for disease outcomes in patients with lupus, we know that patients with chronic diseases have poorer outcomes when they have low socioeconomic status such as educational attainment, low income, and limited access to medical care. Several studies have found an association between lower socioeconomic status and higher morbidity or mortality in African American patients with lupus. In a large multicenter study, lupus disease activity and

health status were most strongly associated with potentially modifiable psychosocial factors such as self-efficacy for disease management (that is, confidence in participating in the management of their own disease). Cumulative organ damage was most highly associated with clinical factors such as age and duration of disease. None of these outcomes was associated with race. These results suggest an important role for psychosocial interventions, to improve confidence in self-management, and coordinated with medical care. These are currently being evaluated in controlled clinical trials.

Broad Objectives:

In lupus, areas of emphasis include defining the biologic mechanisms that underlie increased susceptibility and severity of lupus in minority populations; identifying strategies to reduce health disparities; understanding the natural history, clinical aspects, and responses to treatment and outcomes in patient populations that are disproportionately affected; promoting research on the relationships between socioeconomic status factors and disease outcome; and exploring new strategies to improve the participation of disproportionately affected people in patient-oriented research.

Action Plans:

The NIAMS will continue to fund research studies in all of these priority areas. We will also continue to assess progress in each of these fields through annual progress reports from grantees and are prepared to launch initiatives as needed. These could include scientific meetings to explore the current state of research in lupus, Requests for Applications in targeted areas of research on lupus, or seeking applications for additional specialized centers of research in lupus. The NIAMS will continue to emphasize the importance of discerning the health disparity dimensions of lupus in all affected populations and will give special priority to high quality research applications that address health disparities, including identification of the risk factors involved.

Performance Measures:

Performance will be measured through a number of mechanisms including required annual progress reports from grantees, scientific meetings, and responses to research solicitations that are issued by the NIAMS in lupus research.

Outcome Measures:

The NIAMS will continuously monitor the outcome of the various research programs that it has on lupus and will assess the impact of its programs in advancing lupus research.

Targeted Objective:

One targeted objective is to continue to support the lupus registry and repository and increase the number of people participating in this resource. The goal of the lupus registry and repository is to characterize the genetic basis of lupus in European American, African American, native American patients, as well as to provide high quality clinical data and specimens to investigators working in lupus research.

Action Plans:

To increase the participation of minority individuals in the NIAMS-supported lupus registry and repository.

Performance Measures:

Enrollment in FY 2001 is:

Total: 1209

White, non Hispanic: 848

African American: 288

Hispanic: 61

Native American: 11

Asian: 1

Outcome Measures:

By 2006, the goal is for this registry to include 3262 participants. The plan is that at least 40 percent of the participants will be non-European, to include African American, Native American and Hispanic (Puerto Rican).

Targeted Objective:

The NIAMS-supported LUMINA study (Lupus in Minority Populations: Nature vs. Nurture) is expected to result in three key objectives: (1) identify the MHC and nonMHC genes associated with SLE, including Tumor Necrosis Factor, Interleukin 1 receptor antagonist, and other genes that regulate the cell cycle and cell proliferation; (2) identify the factors that relate disease activity, disease damage and self-perceived functioning as disease progresses; and (3) detect socioeconomic, demographic, clinical immunogenetic,

behavioral and cultural factors contributing to differences in outcomes in three different ethnic groups.

Action Plans:

Complete the final phases of the LUMINA study, including recruiting all patients and verify that required data have been collected.

Performance Measures:

Analyze the data resulting from this study and seek to identify the genes and various factors related to disease activity and disproportionate disease burden in various ethnic groups.

Outcomes Measures:

The identification of either potential genetic factors, disease activity factors, or cultural factors contributing to the disproportionate burden of lupus in minority individuals.

Targeted Objective:

The NIAMS-supported SELENA (Safety of Estrogen in Lupus Erythematosus National Assessment) trial is seeking to establish the safety of hormone replacement therapy in postmenopausal women with lupus. One component of this study is the oral contraceptive study that has three key objectives: (1) to evaluate the safety of oral contraceptives in premenopausal women with SLE; (2) to examine the molecular effects of estrogens on autoimmunity; and (3) to address the risk of thrombosis in women with systemic lupus erythematosus who receive estrogens.

Action Plans:

To increase the participation of minority individuals in the NIAMS-supported SELENA trial.

Performance Measures:

Enrollment in FY 2001 is:

Total: 175

Caucasian: 68

African American: 57

Hispanic: 26

Asian: 23

Other: 1

Outcome Measures:

By 2006, the goal is for 350 patients to be recruited, including 105 African American, 52 Hispanic, 52 Asian, and 140 Caucasian individuals.

C ***SCLERODERMA***

Scleroderma is an autoimmune disorder that occurs much more frequently in women than in men. The hallmark of scleroderma is widespread hardening of the skin. In addition, many forms of scleroderma involve tissues in the lungs, heart, kidneys, intestinal tract, muscles, and joints. In severe cases, scleroderma can be fatal. Although the cause is unknown, researchers believe that both environmental and genetic factors play a role in scleroderma.

While scleroderma affects members of all ethnic groups, it is particularly prevalent in certain Native American people. An important research study funded by the NIAMS blended modern-day genetic marker research and century-old tribal records, using census and historical records dating back to the 1800s. Researchers identified a chromosomal site associated with scleroderma in Oklahoma Choctaw Native Americans. This study suggests that the gene for the protein fibrillin-1 is a possible susceptibility gene for scleroderma. Fibrillin-1 is also known to be responsible for a scleroderma-like condition in a mouse model of the human disease. This work represents the results of an effective public/private partnership, since the NIAMS was joined by other institutes and offices of the NIH, as well as the Scleroderma Foundation/United Scleroderma Foundation, the RGK Foundation and the University of Texas-Houston in supporting this research.

Broad Objectives:

In scleroderma, areas of emphasis include defining the biologic mechanisms that underlie increased susceptibility and severity of scleroderma in minority populations; understanding the natural history, clinical aspects, and responses to treatment and outcomes in patient populations that are disproportionately affected; and fostering and implementing prevention strategies that target disproportionately affected scleroderma patient populations.

Action Plans:

The NIAMS will continue to fund research studies in all of these priority areas in scleroderma. We will also continue to assess progress in each of these fields through

annual progress reports from grantees and are prepared to launch initiatives as needed. These could include scientific meetings to explore the current state of research in scleroderma, Requests for Applications in targeted areas of research on scleroderma, or seeking applications for additional specialized centers of research in scleroderma. The NIAMS will continue to emphasize the importance of discerning the health disparity dimensions of scleroderma in all affected populations and will give special priority to high quality research applications that address health disparities, including identification of the risk factors involved.

Performance Measures:

Performance will be measured through a number of mechanisms including required annual progress reports from grantees, scientific meetings, and responses to research solicitations that are issued by the NIAMS in scleroderma research.

Outcome Measures:

The NIAMS will continuously monitor the outcome of the various research programs that it has on scleroderma and will assess the impact of its programs in advancing scleroderma research.

Targeted Objective:

The NIAMS supports a registry of patients with scleroderma and the key objectives of researchers conducting this registry include characterizing the genetic basis for scleroderma by establishing the recurrence rate of scleroderma within families; establishing the role of immune response and connective tissue regulating genes in disease susceptibility and clinical manifestations; and identifying genome regions linked to diseases using genome scan approaches.

Action Plans:

To increase the participation of minority individuals in the NIAMS-supported scleroderma registry.

Performance Measures:

Enrollment in FY 2001 is 535 patients, 24% African American, and 3% other non European American.

Outcome Measures:

The targeted numbers to be enrolled are 200 in FY 2002; 150 in FY 2003; 100 in FY 2004; and 50 in FY 2005. Overall, 25 percent of these cases are expected to be African America, and about 15 percent Hispanic.

C ***OSTEOARTHRITIS***

Osteoarthritis or degenerative joint disease is the most common form of arthritis. It is painful and disabling and is characterized by the progressive loss of joint cartilage.
Ethnic differences have been noted -- African Americans have a higher risk of both bilateral radiographic (x-ray defined) knee osteoarthritis and hip osteoarthritis than Caucasians. Obesity is associated with bilateral knee and hip osteoarthritis and is a more important risk factor for bilateral knee osteoarthritis in African Americans than in Caucasians. In addition, studies have shown that African Americans have much lower rates of total knee replacement than whites, even when adjusted for age, sex, and insurance coverage.

The NIAMS is encouraging research studies to evaluate risk factors for the development and progression of osteoarthritis in vulnerable populations. Furthermore, the Institute recently sponsored a workshop on the prevention of onset, progression, and disability of osteoarthritis, with sessions aimed at researchers and clinicians, as well as health educators and patients with osteoarthritis. Information and insights from these efforts may lead to the identification and development of potential interventions to treat or prevent osteoarthritis.

The NIAMS is supporting a broad spectrum of studies in osteoarthritis, from the most fundamental that are seeking to learn more about the normal function and survival of cells lining the joints, to clinical studies in which new drugs are being developed, to new prevention strategies.

Broad Objectives:

The NIAMS will undertake a broad range of research activities to address health disparities in osteoarthritis with the goal of understanding better the root causes of health disparities in this most common form of arthritis as well as increasing its activities in this area.

Action Plans:

In osteoarthritis, areas of action include developing a public-private partnership to identify biomarkers for osteoarthritis; following-up on the recommendations made at the July 1999 conference, "Stepping Away from OA: A Scientific Conference on the Prevention of Onset, Progression, and Disability of Osteoarthritis;" and reducing racial disparities in total joint replacement.

The NIAMS will continue to fund research studies in all of these priority areas of osteoarthritis. We will also continue to assess progress in each of these fields through

annual progress reports from grantees and are prepared to launch initiatives as needed. These could include scientific meetings to explore the current state of research in osteoarthritis, Requests for Applications in targeted areas of research on osteoarthritis, or seeking applications for additional specialized centers of research in osteoarthritis. The NIAMS will continue to emphasize the importance of discerning the health disparity dimensions of osteoarthritis in all affected populations and will give special priority to high quality research applications that address health disparities, including identification of the risk factors involved.

Performance Measures:

Performance will be measured through a number of mechanisms including required annual progress reports from grantees, scientific meetings, and responses to research solicitations that are issued by the NIAMS in osteoarthritis research.

Outcome Measures:

The NIAMS will continuously monitor the outcome of the various research programs that it has on osteoarthritis and will assess the impact of its programs in advancing osteoarthritis research.

Targeted Objective:

The NIAMS has recently joined with other NIH components, other federal agencies, and five pharmaceutical companies in funding the newly launched Osteoarthritis Initiative. For the first time, a public-private partnership will bring together new resources and commitment to help find biological markers for the progression of osteoarthritis, a degenerative joint disease that is a major cause of disability in people 65 and older. Over 5-7 years, the Osteoarthritis Initiative (OAI) will collect information and define disease standards on 5,000 people at high risk of having osteoarthritis and at high risk of progressing to severe osteoarthritis during the course of the study. Currently, new drug development for OA is hindered by the lack of objective and measurable standards for disease progression by which new drugs can be evaluated. The Osteoarthritis Initiative will fund as many as six clinical research centers to establish and maintain a natural history database for osteoarthritis that will include clinical evaluation data and radiological images, and a biospecimen repository. All data and images collected will be available to researchers worldwide to help quicken the pace of scientific studies and biomarker identification.

Action Plans:

While it is intended that minorities and women will be represented in proportions similar to those found in the U.S. population of ages 50 to 80, the clinical centers may target specific minority populations for recruitment in their proposals.

Performance Measures:

Applicants for clinical centers in this Initiative could propose to enroll 60% or more of individuals from a specific minority group. While all applications will be ranked on technical merit, but special consideration could be given to those that target minority populations.

Outcome Measures:

The overall study population for the Osteoarthritis Initiative includes at least adequate representation of minority individual, and may include increased representation of minority individuals in individual clinical centers.

C ***VITILIGO***

Vitiligo is a disease of the skin that is characterized by a loss of pigment in all people who are affected. The psychological and social consequences are particularly profound in people of color who are affected.

Vitiligo is a sporadic disease with significant aggregation in families. Thus, it will benefit from molecular genetic approaches and the Human Genome Project. It is a disease of the pigment-producing system, and thus basic research on melanocytes and pigmentation as well as melanoma research will be relevant. It is thought to be an end-organ specific autoimmune disease and so will benefit from research in immunology and autoimmunity.

Broad Objectives:

In vitiligo, areas of emphasis include identifying the gene(s) that are associated with vitiligo, first in the familial cases, and then determining if the same gene(s) are defective in sporadic cases; pursuing a greater understanding of the process of melanogenesis (pigment formation), the molecules involved in the process itself and its control, and changes seen in diseases, such as vitiligo and melanoma; increasing knowledge of the autoimmune mechanisms involved in tissue-specific autoimmune diseases such as vitiligo.

Action Plans:

The NIAMS will continue to fund research studies in all of these priority areas in vitiligo. We will also continue to assess progress in each of these fields through annual progress reports from grantees and are prepared to launch initiatives as needed. These could include scientific meetings to explore the current state of research in vitiligo, Requests for Applications in targeted areas of research on vitiligo, or perhaps seeking applications for

research centers in vitiligo. The NIAMS will continue to emphasize the importance of discerning the health disparity dimensions of vitiligo in all affected populations and will give special priority to high quality research applications that address health disparities, including identification of the risk factors involved.

Performance Measures:

Performance will be measured through a number of mechanisms including required annual progress reports from grantees, scientific meetings, and responses to research solicitations that are issued by the NIAMS in vitiligo research.

Outcome Measures:

The NIAMS will continuously monitor the outcome of the various research programs that it has on vitiligo and will assess the impact of its programs in advancing vitiligo research.

Targeted Objective:

The NIAMS is funding a research project that is seeking to identify the gene(s) involved in vitiligo.

Action Plans:

The study was initiated in FY 2001 and is expected to accrue 1350 individuals in various family groupings over 5 yrs.

Performance Measures:

While 500 individuals have been accrued to date for this study, the full 1350 should be accrued within the next two years.

Outcome Measures:

In addition to recruiting the anticipated number of 1350 individuals, genetic analyses will be conducted over the next five years and it is hoped that genetic factors will be identified.

C ***KELOIDS***

Keloids are an abnormal exuberant form of wound healing in which excessive connective tissue is laid down at the wound site, and is not remodeled normally (as distinguished from hypertrophic scars in which there is excess connective tissue initially, but remodeling takes place

over time). Keloids are seen predominantly in African American individuals.

Keloid development is often sporadic, but there is significant family clustering as well as ethnic and racial differences in prevalence. Thus, advances in molecular genetics and the Human Genome Project will benefit research on keloids. Since the material in the keloid is collagen, laid down by fibroblasts, basic research in collagen synthesis and remodeling, fibroblast biology and growth control, and drugs that affect these processes will aid our understanding of this disease. As keloids are the opposite side of the failure to heal chronic wounds (an area in which the NIAMS has led the coordinated NIH research effort), the advances in this area may have application to the study of keloids.

Broad Objectives:

In keloids, areas of emphasis include identifying the gene(s) for keloid formation, initially in the familial cases, determining the defects, the normal and abnormal protein products of this gene(s), and how these abnormalities produce disease; promoting studies of collagen deposition and remodeling, fibroblast growth and metabolism and its control; applying knowledge from the larger wound healing portfolios of several NIH institutes to the study of keloids, particularly leads derived from animal model systems and clinical trials. Develop additional animal model systems for keloids.

Action Plans:

The current research portfolio in keloids is quite small. The NIAMS will continue to seek research studies in all of these priority areas in keloids. We will also continue to assess progress in each of these fields through annual progress reports from grantees and are prepared to launch initiatives as needed. These could include scientific meetings to explore the current state of research in keloids and Requests for Applications in targeted areas of research on keloids. The NIAMS will continue to emphasize the importance of discerning the health disparity dimensions of keloids in all affected populations and will give special priority to high quality research applications that address health disparities, including identification of the risk factors involved.

Performance Measures:

Performance will be measured through a number of mechanisms including required annual progress reports from grantees, scientific meetings, and responses to research solicitations that are issued by the NIAMS in keloids research.

Outcome Measures:

The NIAMS will continuously monitor the outcome of the various research programs that it has on keloids and will assess the impact of its programs in advancing keloids research.

OTHER RESEARCH

In addition to the targeted areas of research identified above, the NIAMS supports research that contributes to understanding health disparities in other categories as well. Two examples of current research that we fund illustrate what this can include: (1) Studies of the genetics of bone density in Mexican Americans: this study is seeking to identify and characterize the genetic determinants of low bone density. The study population includes adults who previously participated in the San Antonio Family Heart Study, who will now be re-examined and bone density will be measured at three sites. In addition, biochemical markers of bone density-related phenotypes will also be obtained, and candidate genes for osteoporosis will be genotyped. The information that will be learned from this minority population is expected to help us learn more about the role of genetics in bone density in general, and it has profound implications for minority and all populations affected by osteoporosis and other bone diseases. (2) Registry and repository of African Americans with rheumatoid arthritis: the NIAMS currently supports a contract for a consortium for the longitudinal evaluation of African Americans with early rheumatoid arthritis registry, which serves to identify both the genetic and non-genetic prognostic factors of disease outcome using radiographic presence of bony erosions as the primary outcome measure. The registry will serve as the basis for the prospective analyses of factors that are predictive of the clinical phenotype and outcomes. Four major academic medical centers in the southeast United States will gather data which will provide a resource for investigators interested in the genetics of rheumatoid arthritis in African Americans.

These ongoing studies are illustrative of the kinds of special studies that can be taken to understand health disparities. The NIAMS will continue to seek out additional research opportunities in which studies of minority populations provide valuable information to our understanding of common and chronic diseases of bones, muscles, joints, and skin.

HEALTH DISPARITIES CONFERENCE AND RESEARCH SOLICITATION

In December 2000 the NIAMS joined with our colleagues in NIH Office of Research on Minority Health (now the National Center on Minority Health and Health Disparities), the NIH Office of Research on Women's Health, the NIH Office of Disease Prevention, the NIH Office of Behavioral and Social Sciences Research, the Centers for Disease Control and Prevention, the Arthritis Foundation, the American College of Rheumatology, the American Academy of Orthopaedic Surgeons, and the American Academy of Dermatology in cosponsoring a scientific workshop, "Health Disparities in Arthritis and Musculoskeletal and Skin Diseases." The objectives of the conference were to highlight current knowledge about genetic, environmental, social, and behavioral factors that play a role in the marked differences in the prevalence, morbidity, and disability associated with arthritis and musculoskeletal and skin diseases; to identify intervention strategies that could provide models to reduce disparities, and to identify barriers to dissemination of these strategies; and to define challenges and emerging opportunities for research in these areas. The target audiences for this conference included investigators and

practitioners in the fields of rheumatology, orthopaedics, bone diseases, dermatology, epidemiology, genetics, environmental factors, health services, and health education.

The Institute will issue a solicitation for funding in FY 2003 for research in the areas of scientific opportunity identified at this workshop. It will include research opportunities to identify the causes of health disparities in diseases of bones, muscles, joints, and skin.

NIH RESEARCH CAPACITY GOALS

Broad Objectives:

The NIAMS is working to expand opportunities in research training and career development for research investigators from minority and other special populations experiencing health disparities.

Action Plans:

Areas of particular emphasis include targeting the hiring of minority scientists to our research programs, including people at all stages of their careers, and working to promote the training of clinical investigators at Historically Black Colleges and Universities as well as at minority academic health centers.

Performance Measures:

The NIAMS continually monitors its progress in each of the above areas.

Outcome Measures:

The NIAMS anticipates increasing the number of minority scientists at all stages of their careers in its research programs, as well as participating actively in programs focused on clinical training of minority investigators.

Targeted Objective:

To increase the participation of minority scientists training to work in research careers:

Action Plans:

Provide support through mechanisms such as the Predoctoral Fellowships for underrepresented minorities and for students with disabilities; research supplements to support underrepresented minorities and for students with disabilities; Collaborative

Arthritis and Musculoskeletal and Skin Diseases Sciences Awards (CAMSSA); and Clinical Research Education and Career Development Program in Minority Institutions (CRECD).

Performance Measures:

The NIAMS has established targeted numbers in each of these categories.

Outcome Measures:

Awards	FY 2002	FY 2003	FY 2004	FY 2005	FY 2006
# Fellowships	5	5	5	5	5
# Supplements	26	28	29	30	31
# CAMSSA	3	4	4	4	4
# CRECD trainees	1	3	4	4	4

Targeted Objective:

Ensure that minority populations are equitably represented in employment and intramural research training opportunities. Dimensions of this include improving the diversity of the NIAMS work force; increasing the number of underrepresented minority students/graduates trained in the NIAMS summer internship program; and initiating partnerships with schools, organizations or academic centers with substantial minority populations to encourage careers in research.

Action Plans:

A. Continue to monitor and analyze the NIAMS Workforce to determine annual targeted Affirmative Action Planning (AAP) goals. Improve, where needed, representation of minority populations as compared against the civilian labor force available within each AAP job category. Areas of severe under-representation will be especially targeted. For example, Native Americans, African Americans, Hispanics and Asian/Pacific Islanders.

B. Increase number of under-represented applications in the summer internship applicant pool through active recruitment at appropriate meetings and minority schools.

C. Continue mutually beneficial partnership with Wilson High School to encourage students to seek careers in science and to offer summer job opportunities at NIAMS.

D. Continue to participate in NCMHD sponsored internships, such as the Hispanic Youth Initiative.

Performance Measures:

A. Based on the analysis of the workforce, set targeted goals for specific areas to correct severe under-representation.

B. Increase the number of applications/resumes in the minority applicant pool in the summer internship program.

C. Identify NIAMS staff who will serve as science fair judges, lecturers and mentors.

D. Hire qualified minorities from the NCMHD internship program, such as Hispanic Association of Colleges and Universities (HACU), National Association for Equal Opportunity in Higher Education (NAFEO), Washington Internships for Native Students (WINS).

Outcome Measures:

The NIAMS will monitor progress in the growth of each of these 4 areas.

NIH COMMUNITY OUTREACH, INFORMATION DISSEMINATION, AND PUBLIC HEALTH EDUCATION GOALS

OVERVIEW: We are committed to a comprehensive program of information dissemination to patients and to their health care providers. Research advances are of limited value if they never reach the arena of health care, and they miss the goal of improving public health for all Americans. The NIAMS supports information dissemination through three primary means: the Institute's Office of Communications and Public Liaison in the Office of the Director, the National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse, and the NIH Osteoporosis and Related Bone Diseases ~ National Resource Center. In addition, we work closely with many voluntary and professional societies to both learn their needs and views and to disseminate our research findings to them. We have also targeted our information to particular areas of need (including "Lupus: A Patient Care Guide for Nurses and Other Health Professionals" and "The Many Shades of Lupus") and to diverse populations (including printed information and our toll-free information line in English and in Spanish). We will continue to build and strengthen these relationships with the community and will strive to make our information accessible to the vast and diverse populations affected by the diseases within our mandate.

AREAS OF EMPHASIS

C ***COMMUNITY OUTREACH, INFORMATION DISSEMINATION, AND PUBLIC HEALTH EDUCATION***

Targeted Objective in Community Outreach, Information Dissemination, and Public Health Education

Reach out to organizations and health professionals who serve minority, ethnic, and other special populations by staffing exhibits and distributing materials at conferences, meetings, job fairs, and other gatherings.

Action Plans:

Each year, NIAMS develops a plan of exhibits and outreach to national health professional, scientific, and minority organizations via their conferences. We make arrangements to send a display, materials and staff. These conferences are held throughout the year and around the country and include such minority-focused organizations as the National Medical Association, the Minority Health Professions Foundation, the National Hispanic Medical Association, and the American Indian Science and Engineering Society (AISES), as well as scientific and medical organizations in NIAMS areas (such as the American College of Rheumatology).

Timeline/dates:

NIAMS develops exhibit plans the summer before the next fiscal year. The conferences are then held throughout the year, most often in the spring and the fall. We expect to have staffed exhibits at 19 conferences per year and to participate in about 40 health fairs per year.

Performance Measures:

NIAMS keeps records on which meetings we have signed up for, the expected audience, the numbers and types of materials picked up by attendees, and other feedback about the exhibit and the conference.

Outcome Measures:

Success of each exhibit is judged in terms of materials distributed, numbers of people visiting the booth, contacts made, and follow up requests. We keep track of this information and adjust our exhibit plans accordingly for the next year.

Targeted Objective in Public Information, Outreach, and Education

Develop public information materials about arthritis, musculoskeletal, and skin diseases for populations disproportionately affected by these conditions.

Action Plans:

NIAMS has been--and will continue to be--engaged in identifying and developing materials aimed at reducing health disparities by educating affected populations about disease treatment and prevention. The Institute already has in place a rigorous process for determining what materials should be developed, and biennially solicits input from NIAMS staff and clearinghouse, voluntary health and professional organizations, and members of its Advisory Council. Bilingual materials and materials for those of other cultures, languages, and literacy levels continue to be developed and pretested before distribution. Examples of NIAMS publications addressing diseases that affect certain populations disproportionately include: *Handout on Health: Osteoarthritis, Handout on Health: Systemic Lupus Erythematosus, the Lupus Nurses Guide, the Many Shades of Lupus, Handout on Health: Scleroderma, Questions and Answers About Vitiligo,* and an information packet on keloids. Publication plans for 2002-2006 include a booklet on autoimmunity and a number of Spanish-language summaries on such subjects as back pain and gout. Publications such as these generally take 6-12 months to clear and produce, and can cost between $1K and $70K, depending on the type of document and the number printed.

Publications are promoted through the Consumer Information Center and notices to lay and professional groups. They are frequently distributed in bulk to intermediaries, and are available on the NIAMS Web site. In addition, Spanish speakers can access our toll-free information line in their language.

A publications plan for FY2002-2003 is now being finalized and will be reviewed and adjusted as it is carried out. A new plan for FY2004-2005 will be developed by Fall 2003, and one for FY2006-2007 by Fall 2005.

Performance Measures:

Demand for and value of our publications is assessed through distribution reports from the NIAMS clearinghouse, through comments in letters and e-mail messages, through "hits" to our Web pages, through responses to promotional initiatives, and through Consumer Information Center monthly distribution reports. Our publications plan is evaluated every 2 years with input from voluntary and professional organizations and the NIAMS Council.

Outcome Measures:

Although it is difficult to measure the direct health impact of our publications, we consider increased distribution of publications a positive indicator. We will continue to monitor our own direct distribution numbers, and will continue our association with secondary distributors, like voluntary agencies and the Consumer Information Center, who have so dramatically increased our readership.

Targeted Objective in Outreach through the Health Partnership Program

Objectives:

To reduce morbidity and mortality associated with rheumatic, musculoskeletal, and skin diseases and their complications for populations disproportionately affected by these conditions through four program areas: public health education, patient care, access to clinical investigations, and recruitment to research careers.

This objective reflects feedback from leaders of the Washington, D.C. area community and local voluntary organizations during bi-annual meetings that began in February 2000.

Action Plans:

In the first phase of this program, we are implementing a model community-based research program to study rheumatic diseases in the African American and Hispanic/Latino communities in the metropolitan, Washington, D.C. area. We will expand the program to include additional minority groups and localities in future phases of the program.

Through collaborations with community leaders, we have developed the NIAMS Community Health Center which provides researchers the opportunity to (1) increase understanding of health disparities in rheumatic diseases, (2) provide health care to the community, (3) increase participation of minorities in research studies, (4) increase the number of underrepresented biomedical researchers, and (5) train NIAMS medical residents to care for patients from minority communities. The health center opened in July 2001. Patients are seen under the Natural History of Rheumatic Diseases protocol, which is conducted by investigators from the Institute's Intramural Research Program. Because rheumatic diseases are chronic conditions, the study will be conducted through several fiscal years. Researchers expect to develop related health disparities studies based on outcomes of the Natural History protocol.

Health education is an important component of the program that includes developing brochures and factsheets and conducting arthritis education seminars.

Program Goals:

The goals for the first phase of the HPP are to (1) increase awareness and understanding of rheumatic diseases and the importance of early detection and treatment in preventing complications and chronic disabilities associated with these diseases, (2) Increase awareness of and access to clinical investigations on rheumatic diseases, (3) increase the number of underrepresented minority investigators at the NIAMS and in the biomedical research fields related to rheumatic diseases, and (4) evaluate the impact of providing access to and medical care for patients who have rheumatic diseases.

Performance Measures:

Community participation in health disparities research through the health center, requests for health materials and seminars by community members, and participation of minority students and researchers in HPP activities are indications of program success.

Outcome Measures:

The NIAMS will use these procedures to measure and evaluate the outcomes of the goals listed:

(1) Requests for health information, clinical studies, and seminars will be tracked by staff of NIAMS and the NIAMS Information Clearinghouse.
(2) Patient visits to the health center will be monitored on a continuous basis.
(3) Participation in events and programs that focus on minority research recruitment will be tracked.
(4) Feedback from community leaders and representatives will be obtained on a continual basis to measure our success in meeting the program's objective.

CONCLUSION

Many diseases within the mission of the NIAMS disproportionately affect people in minority populations. The NIAMS Strategic Plan for Reducing Health Disparities serves as a complement to our Institute's Strategic Plan for FY 2000 - 2004, and will serve as a guide for our future efforts to address and decrease these health disparities. Both of these plans are posted on the NIAMS Web site. We recognize that these documents are fluid and we anticipate continuing to update them from time to time based on scientific progress as well as comments we receive from the scientific communities as well as the American public.

NIAMS Health Disparities Budget
(Dollars in Millions)

Institute / Center	FY 2002			FY 2003		
	Research	Infrastructure	Outreach	Research	Infrastructure	Outreach
NIAMS	$41.90	$1.60	$0.50	$45.50	$1.70	$0.50